



## Transitional experience of men with breast cancer from diagnosis to survivorship: An integrative review



Ahtisham Younas<sup>a,e,\*</sup>, Amara Sundus<sup>b,c</sup>, Shahzad Inayat<sup>d</sup>

<sup>a</sup> Memorial University of Newfoundland, Canada

<sup>b</sup> School of Nursing, Foundation University, Islamabad, Pakistan

<sup>c</sup> Quality Assurance Officer, Ali Medical Hospital, Islamabad, Pakistan

<sup>d</sup> College of Nursing and Al-Nafees Medical College, Isra University, Islamabad, Pakistan

<sup>e</sup> Shifa College of Nursing, Islamabad, Pakistan

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### ABSTRACT

**Purpose:** The care needs, experiences, and physical and psychological health of women with breast cancer are well-documented, but missing is the discussion of illness and management experiences of men with breast cancer. To explore and understand the nature and complexity of transitional experiences, from the time of receiving the diagnosis to the survivorship of men with breast cancer.

**Methods:** An integrative review was conducted according to Whittemore and Knaf's methodology. Literature was searched in seven scientific and two grey literature databases using mesh terms “breast cancer”, “men”, “experiences” and “nursing”. Of 1013 screened articles, 17 qualitative, quantitative, and mixed methods studies and research reviews met the inclusion criteria. The studies were critically appraised using mixed methods appraisal tool and rated as high and low quality. The data was extracted using literature summaries and synthesized using thematic, descriptive, and interpretive analysis.

**Results:** Nine themes captured the transitional experience at the diagnosis, management, and survivorship stages. Gender inequalities and stigmatizations at personal, health care, and social and community levels negatively influence men's experiences.

**Conclusions:** The gender stigmatizations present at personal, health care, and social and community levels greatly influence men's experiences of breast cancer. To resolve gender inequalities in breast cancer management, the nurses should focus equally on the needs of men and women with breast cancer. The needs of men entail reducing health care and social stigmatizations, gender specific information and management, and opportunities to participate in support groups.

## 1. Introduction

Breast Cancer (BC) is considered a woman's disease because it is more prevalent in women (Midding et al., 2018), but men are also at risk of developing BC. The overall prevalence for Male Breast Cancer (MBC) ranges from 0.5 to 1% (Ruddy and Winer, 2013), but incidences are reported regularly. Approximately 390 men are diagnosed annually in the UK (Cancer Research UK, 2017) and 25 in New Zealand (Breast Cancer Foundation New Zealand, 2018). An estimated 2670 cases of MBC were reported up to 2019 in the US (American Cancer Society, 2019), 230 cases in 2017 in Canada (Canadian Cancer Society, 2019), 140 cases in 2014 in Australia (Cancer Council Australia, 2018) and 149 from 2012 to 2016 in Nordic Countries (Danckert et al., 2019). The estimated deaths of men with BC includes, 28 deaths in 2014 in

Australia (Cancer Council Australia, 2018), 60 deaths in 2017 in Canada (Canadian Cancer Society, 2019), and about 500 men will die from BC in the US in 2019 (American Cancer Society, 2019). The incidence of MBC in 25 countries for the 1998–2002 (Ly et al., 2013) is reported in Table 1.

Given the increasing trends of BC in men, considerable efforts have been devoted to better understand the biological and epidemiological features; gender differences in the clinical presentation of BC; treatment modalities; diagnostic factors; prognosis; and outcomes of BC in men (Giordano, 2018; Fentiman, 2018). The epidemiological features, oncological reasons of occurrence, and stages of BC are similar between men and women. However, key differences exist in the course of the illness: men are diagnosed at a later stage of life because most of the chest symptoms are misdiagnosed as gynecomastia and men tend to be

\* Corresponding author. 174 Patrick Street, A1C 5C4, St. John's, Newfoundland, Canada.

E-mail address: [ay6133@mun.ca](mailto:ay6133@mun.ca) (A. Younas).

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**Table 1**  
Incidence of male breast cancer from 1998 to 2002.  
Source: Ly et al. (2013).

Country	Incidence/per 100,000 man-years
India	0.42
Israel	1.24
Japan	0.18
Philippines	0.98
Singapore	0.23
Thailand	0.16
Austria	0.45
Denmark	0.54
Estonia	0.49
France	0.77
Iceland	0.93
Italy	0.83
Netherlands	0.51
Poland	0.50
Slovakia	0.48
Spain	0.50
Switzerland	0.55
UK	0.50
Brazil	0.48
Canada	0.59
Columbia	0.23
Costa Rica	0.30
Ecuador	0.29
USA	0.72
Australia	0.55

seen with more severe symptoms of BC (larger tumors and regional nodal metastases) (Greif et al., 2012; Fentiman, 2018; May, 2018). Men are more likely to reach an advanced stage, which makes them susceptible to poor prognosis and lowered chances of survival (Greif et al., 2012; Liu et al., 2018; Lautrup et al., 2018). The overall survival rate for men with BC is 82.8% compared to those of women, that is, 88.5% (Liu et al., 2018). Lautrup et al. (2018) reported the 5 and 10 year survival rate of men with BC in Denmark to be 55.1% and 31.7% respectively. This survival rate is lower than those of women's rates of 76.8% and 59.3% for 5 and 10 years respectively. The most important difference between BC in men and women is the personal reactions to and social impacts of BC, effect of treatment modalities on self, and the nursing and health care needs of both genders (Giordano, 2018; Quincey et al., 2016; Fentiman, 2018). In nursing the care needs, experiences, quality of life, and psychological health of women with BC are well-documented (Remmers et al., 2010; Cebeci et al., 2012; Cobocuenca et al., 2018). Unfortunately, missing is a discussion of illness and management experiences of men. Gaining this information is important because patients' stressors and coping mechanisms may change across transitional stages of illness. Gaining this understanding is also essential to develop an effective care plan for the men who receive care within different oncology settings such as inpatient, surgical, and palliative care, and at different stages of illness.

Developmental, situational, organizational, and health-illness transitions have been an area of nursing research and theory. Meleis (2015) in her transitions theory, articulated the process, nature, response patterns, and health outcomes of the above listed kinds of life transitions. This paper focuses on health illness transition, which are the transitions related to person's health and illness state and general well-being. Each transition experience entails five properties: time span, process, disconnectedness, awareness, and critical points. Time span is the time when individuals becomes aware of the transition. Process refers to the continuous and dynamic nature of the transitional experience. Disconnectedness refers to a disruption in the roles and attitudes of individuals due to the transition. Awareness is cognizance of individuals about the triggers, processes, and other changes due to the transition. Critical points are the turning points in one's transition which positively or negatively affect the transition (Meleis, 2015).

Each transition is also facilitated or inhibited by different factors such as personal, community, societal, and global factors. Personal conditions are one's knowledge, attitudes, values, and meanings attached to the transition. Community conditions are the available support groups including friends and family who can help in achieving a smooth and a healthy transition. Societal conditions are the norms and traditions of the society where individuals live and grow up. Global conditions are the policies of the government and other organizations which directly and indirectly influence individuals' life style and health (Meleis et al., 2000; Meleis, 2015). Given that transitional experiences are multifaceted, it is essential to delineate the transition experience of men with BC.

Reviews about MBC have been conducted in medicine (Giordano, 2018), medical sociology (Quincey et al., 2016), and nursing (Nemchek, 2018). Giordano (2018) provided an unsystematic review to determine the epidemiological, pathological, and clinical features and prognosis and treatment modalities of BC. Quincey et al. (2016) conducted a meta-synthesis to describe the impact of marginalization of men with BC on their psychosocial and psychosexual health. Nemchek (2018) examined reasons for gender disparity and interventions to address the gender disparity issues. The common reason for gender disparity was lack of information about MBC and men not receiving the interventions that are used for female patients. The review highlighted the need for nurses to support and advocate for men with BC and a need to examine men's experiences of BC. The findings of these reviews, although very useful, provided limited understanding about the overall transitional experiences of men with BC and no specific implications for nurses. The focus of nursing is to provide holistic care to patients and there has been growing interest in palliative care of patients. Holistic care "refers to the provision of care to patients that are based on a mutual understanding of their physical, psychological, emotional, and spiritual dimensions. In addition, holistic care emphasizes the partnership between nurse and patient and the negotiation of healthcare needs that lead to recovery" (Jasemi et al., 2017, P. 76). Therefore nurses should be made aware of the illness experiences of men with BC in order to provide holistic care.

Although cases of BC in men are rare, nurses should be able to discern the best possible management of such patients so as to improve their care quality (Al-Haddad, 2010). A limited knowledge about BC in men; the needs of men with BC; and the impact of BC on men and their quality of life; places men at a disadvantage (Lewis-Smith, 2016). This could negatively affect the received nursing care. Therefore, it is essential to understand the experiences and needs of men with BC in order to ascertain how nurses can better provide holistic care for men who receive a diagnosis of BC.

### 1.1. Purpose

To explore and understand the nature and complexity of transitional experience, from the time of receiving the diagnosis to the survivorship, of men with BC. The research question was: What is the nature and complexity of experiences of men from the time of receiving the diagnosis of BC to survivorship?

## 2. Methods

### 2.1. Design

We conducted an integrative review as it allows the inclusion, appraisal, and synthesis of a range of qualitative, quantitative, and mixed research. The steps included: a) problem identification, b) literature search, c) data evaluation, and d) data analysis (literature summary tables, coding, thematic analysis, and narrative summaries were used to analyze the data, then synthesized using both descriptive and interpretative summaries) (Whittemore and Knaf, 2005).

## 2.2. Search strategy

We performed a three-step literature search using the search terms and phrases: “breast cancer in men”, breast cancer AND/OR neoplasms in men AND experiences”, “breast cancer in men AND nursing”, “breast cancer AND men OR/WITH experiences”, and “male breast cancer AND experiences”. First, a search of PubMed and Cumulative Index of Nursing and Allied Health Literature (CINAHL) to identify the indexed terms and relevant articles. Second, an electronic search of databases (Science Direct, EMBASE, Google Scholar, Scopus, and OVID), was undertaken to identify literature published from December 1999–December 2018. We chose a wide time frame because of the dearth of research on the topic. A grey literature search was performed in Open Grey and OAIster. Additional search was performed in the Journal of Men's Health and American Journal of Men's Health and in the reference lists of the selected studies.

## 2.3. Search outcomes

Initial search generated 83,896 results in all the databases including the grey literature databases. The search was limited to research and reviews, and editorials, letters, opinion pieces, reports, commentaries, books, and book chapters were excluded, resulting in 7801 records. The duplicates were further removed, leaving 1013 articles. These articles were screened after reviewing the titles and abstracts. This screening resulted in the exclusion of articles focused on molecular and diagnostic approaches for BC, prostate cancers in men, men caring for spouses and women with BC, and cancers in lesbian, gay, homosexual and bisexual individuals. Based on this screening, 24 articles were selected for full-text screening. The inclusion criteria were: a) English language research and reviews with men with BC as the target population, b) articles focused on the experiences, needs, and perspectives of men with BC at any stage of the illness after receiving the diagnosis, and c) dissertations focused on the very topic. This final screening resulted in the exclusion of one article in the Spanish language, one article that included BC nurses as sample, one article that explored perspectives of men at risk of BC, and four articles that explored the knowledge and perceptions of male university and college students about BC in men. The supplementary search of the journals and the reference lists resulted in no additional studies. Finally, 17 articles were included in this review (Fig. 1).

## 2.4. Data evaluation and appraisal

The final sample comprised original qualitative, quantitative, and mixed methods studies and research reviews. These studies were critically appraised using the Mixed Methods Appraisal Tool (Hong et al., 2018). Due to a very limited number of studies, the quality scores were not assigned so that all the studies could be synthesized and interpreted. However, studies were rated as high and low quality and during synthesis the findings from high quality studies were given more weightage, and low quality studies were used to support the synthesized findings. All of the reviewers independently appraised and rated the studies. The ratings were compared and discussed, discrepancies were resolved, and consensus was reached.

## 2.5. Data analysis and synthesis

Three reviewers independently analyzed and extracted study findings using summary tables which entailed information about the authors, country, study purpose, study design, research methods, sample and its characteristics, major findings, and strengths and limitations. The data extraction sheet was developed after discussion among the researchers. For data synthesis, the major findings were described and interpreted using coding, thematic analysis, and narrative summaries. The codes were extracted from the qualitative studies and the

interpretation of findings presented by the study authors, and narrative summaries were used to synthesize the findings from the quantitative studies. One page summary for each article was developed which included core findings in each stage of transition. Joint matrices were developed to compare qualitative, quantitative and mixed findings and then the findings were collated into themes. In each matrix the core findings from each stage were placed and then combined to develop the themes. At the end of this synthesis, one of the researchers verified the developed themes with the findings from primary studies. The inter-rater agreement was assessed using Kappa statistic. The overall agreement was 0.92 which indicates an almost perfect agreement (McHugh, 2012).

## 3. Findings

### 3.1. Study characteristics and quality appraisal

Of 17 studies, ten studies were qualitative (France et al., 2000; Williams et al., 2003; Iredale et al., 2006; Donovan and Flynn, 2007; Sime, 2012; Halls, 2013; Pituskin et al., 2007; Naymark, 2006; Duarte do Amaral et al., 2017; Quincey, 2017), five quantitative (Brain et al., 2006; Iredale et al., 2007; Andrykowski, 2012; Ruddy et al., 2013; Kipling et al., 2014), and one each were mixed methods (Midding et al., 2018), and meta-synthesis (Quincey et al., 2016). Most of the studies were conducted in the UK (n = 11), followed by Canada (n = 2), the USA (n = 2), Germany (n = 1), and Brazil (n = 1). The quality was rated to be high for 12 studies and low for five studies. The target population mainly included men with BC who were at all three stages, that is, diagnosis, management, and survivorship. However, three studies focused on BC survivors (Andrykowski, 2012; Ruddy et al., 2013; Duarte do Amaral et al., 2017). Two studies included a secondary sample of health care professionals (Naymark, 2006; Halls, 2013) and one study included a secondary sample of women with BC (Sime, 2012). The common methods for data collection were semi-structured and in-depth interviews and focus groups. In quantitative studies, a variety of data collection tools were used (i.e., hospital anxiety and depression scale, cancer-specific distress and coping scale, the body image scale, COPE scale, behavioral risk factor surveillance system survey, expanded prostate index composite, hormonal and sexual subscales, and functional assessment of BC therapy). Two studies used newly developed scale (Kipling et al., 2014; Iredale et al., 2007) and one study combined extended interviews with self-authored photographs of the participants (Quincey, 2017).

For quality appraisal the sample size was not considered a quality criterion because of low prevalence of BC in men. All of the studies clearly stated the inclusion and exclusion criteria and the sample size ranged from 02 to 161, recruited using purposive (n = 12), convenient (n = 3), and random sampling (n = 1). For the meta-synthesis a clear research question and inclusion and exclusion criteria for the studies was stated. For qualitative studies, the main limitations of the studies included: lack of contextual information, incomplete or inadequate data analysis resulting in premature closure of thematic analysis, no bracketing of researchers' personal views on the data analysis, and lack of rich description of study findings. For low rated quantitative studies, no information was provided about the psychometric properties of data collection tools and sample size calculation, data was collected from a single setting, convenient sampling was used, and missing data were reported. The mixed methods study was rated as high because the justification for the use of mixed methods was made explicit and integration occurred at various dimensions such as data collection, data analysis, interpretation, and conclusion. All of the studies did not discuss the study findings in terms of the context and culture, thereby failure to enhance the understanding of study findings (Table 2).

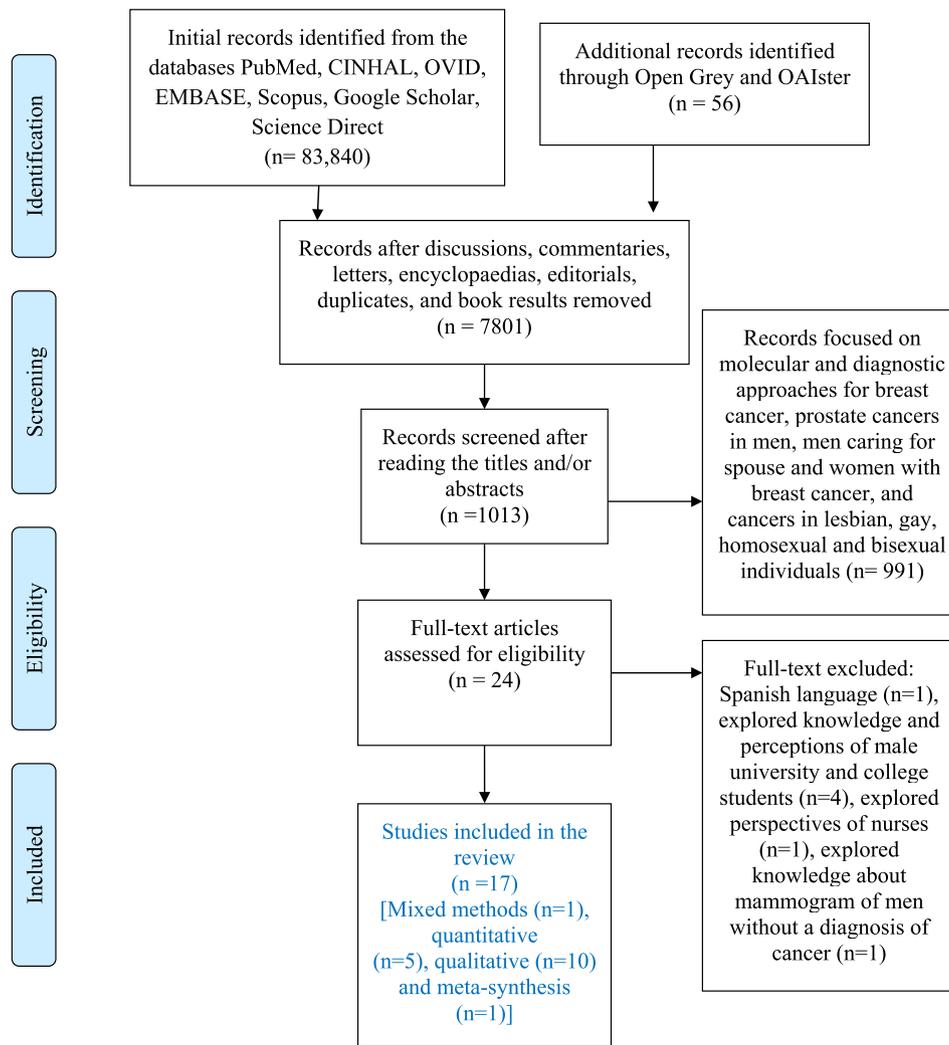


Fig. 1. Literature search strategy.

### 3.2. Themes

Nine themes fully captured the transitional experience at stages: diagnosis, management, and survivorship. However, one core theme was consistent across all three stages and influenced the overall transitional experience. Each of the theme is discussed as follows (Table 3). (See Fig. 2)

## 4. Transition stage 1: diagnosis of breast cancer

### 4.1. Fluctuating emotional and physical reactions

Men received the diagnosis of BC weeks and months after discovering the initial symptoms which included breast pain, moles, brown marks (France et al., 2000), bruised nipple, swollen breast, skin outgrowth (Sime, 2012), and lumps and inverted nipples (Iredale et al., 2007). The age range at the time of diagnosis was 63–66 years (Pituskin et al., 2007; Iredale et al., 2007; Middling et al., 2018). The men described receiving a diagnosis of BC as an emotionally and physically challenging experience as it was mostly associated with negative feelings of denial, shock, disbelief, and self-blaming. Some men demonstrated their denial with the question “Why me?” (Donovan and Flynn, 2007, p. 4) and “how the dickens did I get breast cancer” (Iredale et al., 2006, p. 336), while others felt “stupid” (Halls, 2013, p. 109), and “foolish” (Naymark, 2006). Iredale et al. (2006) reported that 84% (135/161) men were shocked at receiving the diagnosis. In addition, to

emotional reactions, the physical reactions to diagnosis included sighs, drooping of shoulders, and exhaling loudly at receiving the diagnosis (Halls, 2013).

Although most men had negative reactions to their diagnosis, some men experienced less embarrassment and accepted their diagnosis. Kipling et al. (2014) reported that 52 out of 78 men (72%) were not embarrassed to see their doctors for assessment and 42 (54%) had no negative reactions to the diagnosis. The acceptance of the diagnosis was associated with prior knowledge about MBC (Sime, 2012). Those men who learned about the existence of BC in men through media campaigns, magazines, and other news sources were less likely to experience negative emotions (Halls, 2013). In summary, men's reactions to the diagnosis fluctuated based on their context and prior knowledge of BC.

### 4.2. Strategic and arduous disclosure

The men mostly struggled to disclose their diagnosis to family, friends, and other members of the community. The first concern was to disclose the diagnosis to spouses, children and family members; some disclosed the diagnosis to their spouses without any hesitation and embarrassment and received support from them to seek further medical care (Sime, 2012; Halls, 2013), while others concealed their diagnosis and took their time before disclosing it (Donovan and Flynn, 2007; France et al., 2000) due to fear of stigmatization, embarrassment, (Sime, 2012). Others disclosed their diagnosis in order to raise

**Table 2**  
Literature summary tables.

Authors & Country	Purpose	Design	Sample	Methods	Core Findings	Quality Appraisal
France et al. (2000) UK	To explore psychological and social consequences of breast cancer in men.	Phenomenology	Purposive, 8 men who completed a course of radiotherapy and/or chemotherapy	Unstructured interviews for data collection and content analysis for analysis.	Six categories: delay in diagnosis, shock: a reaction to diagnosis, stigma, body image, casual factors, and provision of information, emotional support and counseling.	<b>Strengths:</b> Rich narratives and transferable findings <b>Limitations:</b> lack of contextual information, no description of the relationship of context and researcher, and no bracketing <b>Quality rating:</b> High <b>Strengths:</b> large sample <b>Limitations:</b> lack of contextual information, no description of the relationship of context and researcher, no rich description of narratives, no bracketing, and premature closure of data analysis, <b>Quality rating:</b> low
Williams et al. (2003) UK	To explore experiences of men with breast cancer	Qualitative description	Purposive, 27	Focus groups using a semi-structured guide and thematic analysis for data analysis.	Four categories: diagnosis, disclosure, support, and gender-specific information.	<b>Strengths:</b> large sample, valid and reliable scales and diverse sample <b>Limitations:</b> Missing data (11) and cross-sectional design limits the casual relationship of variables <b>Quality rating:</b> High
Brain et al. (2006) UK	To determine the prevalence of psychological distress in men with breast cancer and the factors associated with increased distress.	Cross sectional survey	Convenient, 161	Hospital anxiety and depression scale, cancer-specific distress, the body image scale, and COPE scale	The anxiety score was 3.73, the depression score was 2.76, and distress 10.30. Higher scores were reported in men who underwent mastectomy and had comorbidities. Anxiety was most strongly associated with avoidance coping and fear and uncertainty about the future (42% variance in anxiety scores, $p < .001$ ). Depressive symptoms were associated with altered body image (35% variance, $p < .001$ ). In total, 86% of participants received the diagnosis from a surgeon, 80% shared the diagnosis with their close family and friends, 92% only received verbal information on breast cancer, 19% spoke to other men about their condition. Only 1% of participants reported depression, 6% anxiety, and 23% reported cancer specific anxiety. Main qualitative themes: Diagnosis and disclosure, information needs, support, and raising awareness	<b>Strengths:</b> Use of mixed methods approach to develop a comprehensive understanding, rich description and integration of both datasets, and robust data analysis. <b>Limitations:</b> Minimal information about the validity and reliability of questionnaire <b>Quality rating:</b> High
Iredale et al. (2006) UK	To explore men's experiences of being diagnosed with breast cancer	Cross sectional survey along with focus groups	Purposive, 161	Hospital anxiety and depression scale and cancer-specific distress and coping scale for data collection, descriptive analysis for quantitative and thematic analysis for qualitative.		<b>Strengths:</b> Diverse sample from Australia, England, and America <b>Limitations:</b> No formal data analysis method, no qualitative themes, and limited information about the context, and no bracketing <b>Quality rating:</b> Low
Naymark (2006) Canada	To explore the gendered distinction of breast cancer information, support services, treatment options and research efforts as hindrances in establishing an early diagnosis of male breast cancer.	Exploratory Qualitative	Purposive sample of 6 men with breast cancer and 5 health care professionals.	In depth interviews	Gender dependent factors such as breast cancer is a women disease, lack of information about male breast cancer, and masculinity affected the early diagnosis.	<b>Strengths:</b> Use of mixed methods approach to develop a comprehensive understanding, and integration of both datasets. <b>Limitations:</b> Minimal information about the validity and reliability of questionnaire, no rich description of data, and single setting. <b>Quality rating:</b> low
Iredale et al. (2007) UK	To explore men's perceptions of information needs and how to meet the needs.	Cross sectional survey with interviews	Purposive, 161	Anonymous questionnaire and interviews, descriptive and thematic analysis	In terms of general information about breast cancer, 91% of men received verbal information, 71% received leaflets, and 53% received booklets. Nurses were described as most helpful information providers. Regarding, gender specific information, 60% of participants needed more information. Young men wanted more information ( $X^2 = 23.45$ ,	

(continued on next page)

Table 2 (continued)

Authors & Country	Purpose	Design	Sample	Methods	Core Findings	Quality Appraisal
Donovan and Flynn (2007) UK and overseas	To explore lived experiences of men with breast cancer	Phenomenology	Purposive sample of 5 men from the UK and 10 email correspondences from overseas	Semi-structured interviews, email correspondences, thematic analysis	p = 0.001). Generally, patients considered that the information provided was helpful. Four major themes: Living with male breast cancer, a contested masculinity, concealment as a strategy to manage the diagnosis, and interacting with health services.	<b>Strengths:</b> Rich narratives, diverse sample, and adequate contextual information <b>Limitations:</b> limited description about data analysis and use of correspondences which could have resulted in minimal understanding of experiences. <b>Quality rating:</b> High <b>Strengths:</b> large sample and rich information about the context <b>Limitations:</b> premature closure of themes and mainly included only white men
Ptuskin et al. (2007) Canada	To describe the experiences of men with breast cancer	Exploratory Qualitative	Purposive sample of 20 men	In depth interviews	Major themes included, disclosure, coping, support, lack of information, body image, and a new life	<b>Quality rating:</b> High <b>Strengths:</b> Baseline comparability of comorbidities of cases and controls <b>Limitations:</b> small sample of cases and chances of misclassification bias. <b>Quality rating:</b> High
Andrykowski (2012) USA	To determine the physical and mental health status and health behaviours of male breast cancer survivors	Case control	Random sample, 66 cases and 198 controls	Behavioral risk factor surveillance system survey	The cases reported poor life satisfaction (1.78, SD 0.76 vs 1.53, SD 0.55, Effect size 0.41), poor physical health (3.15, SD 1.19 Vs 2.70, SD 1.07, Effect size 0.40) and limitations in physical, emotional, and mental activities (47% vs 22%, OR = 3.17; CI = 1.76–5.71) Similar health seeking practices of men and women. Contrary to women, men used strategic announcing to disclose the illness, received little information and limited treatment choices, had negative experiences in the clinic and ward setting; were mistaken as supporters not as the patient, experienced suspicion from female patients and were not given adequate resources to manage their treatment. Men's wives played a supportive and essential role in helping men deal with the challenges.	<b>Strengths:</b> Large and diverse sample, context explicitly described, researcher identified herself in the context <b>Limitations:</b> Use of secondary data for women's sample <b>Quality rating:</b> High
Sime (2012) UK	To compare men's and women's experiences of having breast cancer	Qualitative	Purposive sample of 19 men and 23 women	Interviews, thematic analysis for data analysis	As a result of endocrine therapy, men reported a decrease ability to perform sex (Mean = 43.5, 20.1) and increased hormonal symptoms (Mean 80.3, 15.6)	<b>Strengths:</b> Valid and reliable tools <b>Limitations:</b> Chances of response bias, single setting, and a small sample comprised of white and educated men, and incomplete data. <b>Quality rating:</b> Low
Ruddy et al. (2013) USA	To explore quality of life, distress, fertility, and genetic issues in men who survived breast cancer.	A cross-sectional survey	Convenient, 42	Expanded prostate index composite, hormonal and sexual subscales, hospital anxiety and depression scale, functional assessment of cancer therapy breast.	Form the diagnosis to management, men experienced hegemonic masculinity, they did not receive adequate information and were not fully informed about treatments, and marginalization was prominent.	<b>Strengths:</b> Data triangulation, researcher identified himself in the context, diverse sample from various countries, <b>Limitations:</b> small sample for interviews <b>Quality rating:</b> High <b>Strengths:</b> comparative analysis of survey and literature review and large
Halls (2013) UK	To explore men experiences of breast cancer	Qualitative	Purposive sample of 3 men, interviews with 4 health providers,	Semi-structured interviews, media analysis, forums, data analysis using discourse analysis	Literature review identified that men experience shame, stigma, anxiety,	(continued on next page)

Table 2 (continued)

Authors & Country	Purpose	Design	Sample	Methods	Core Findings	Quality Appraisal
Kipling et al. (2014) UK	To explore the psychological impact of breast cancer and the breast cancer assessment clinic.	A narrative review and a cross-sectional survey			loneliness, and unfairness. In survey, men generally had positive opinions; 78% reported positive clinical experience. Only 28% indicated that they are embarrassed to see the practitioner, 20% felt embarrassed, and 32% were anxious. Main themes: Negotiating the complexities of diagnosis and disclosure, navigating multiple layers of marginalization, and re-establishing masculinities	sample <b>Limitations:</b> limited information about validity and reliability of questionnaire and open-ended questions were used, but analysis was not presented. <b>Quality rating:</b> High
Quincey et al. (2016) UK	To describe the impact of marginalization of men with breast cancer, on their psychosocial and psychosexual health and social milieu	A meta-synthesis	8 studies	Meta-ethnographic analysis		<b>Strengths:</b> Comprehensive and extensive literature search and robust analysis and synthesis <b>Limitations:</b> a limited number of studies; inclusion of only qualitative studies, and no quality assessment <b>Quality rating:</b> High
Duarte do Amaral et al. (2017) Brazil	To explore context of men who survived breast cancer	Qualitative	Purposive, 2	Semi-structured interviews and thematic analysis	Three themes: The discovery of breast cancer, coping with breast cancer survivor, and sources of support	<b>Strengths:</b> Rich narratives and adequate contextual information <b>Limitations:</b> small sample, no rich narratives, no description of the relationship of context and researcher, and no bracketing, and premature thematic closure.
Quincey (2017) UK	To explore and understand the illness experiences of men with breast cancer	Phenomenology	Purposive sample 31 men	Self-authored photographs extended semi-structured for data collection	Main theme: Threatened and exposed masculinity, protected and asserted, and reconsidered and reconfigured.	<b>Quality rating:</b> low <b>Strengths:</b> Rich narratives, adequate contextual information, diverse and large sample, multiple methods, and transferable findings <b>Limitations:</b> no description of the relationship of context and researcher
Midding et al. (2018) Germany	To understand the meaning of suffering of men with breast cancer and the stigmatization attached to breast cancer	Mixed methods	Purposive 27 for qualitative and 100 for the survey.	Survey and interviews, descriptive analyses and thematic analysis, joint display for mixed analysis	The greatest stigmatization was experienced in the cancer care settings (mean 1.5, SD 0.96) particularly during hospitalization (Mean 1.2, SD 0.6), and exclusion in the working environment (Mean = 1.69, SD0.78). Major themes: Context of stigmatization, categories of stigmatization, and stigma types.	<b>Quality rating:</b> High <b>Strengths:</b> Rich narratives, adequate contextual information, fully integrated datasets, robust tools, and diverse sample. <b>Quality rating:</b> High

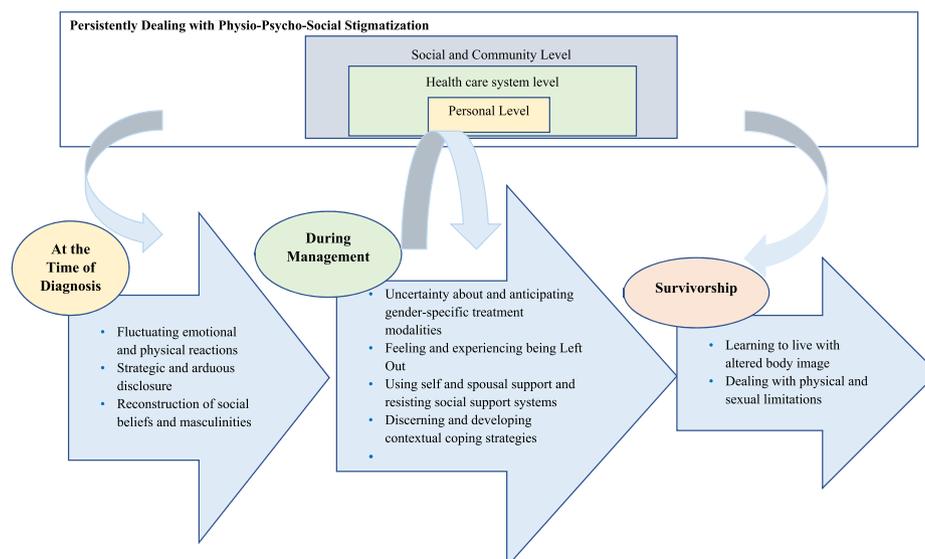
**Table 3**  
Themes and supporting quotes.

Themes	Supporting Quotes from the Reviewed Studies
Persistently Dealing with Physio-Psycho-Social Stigmatization	<p><b>Social and Community Level</b> “I didn’t feel any embarrassment, I told friends it was just an operation to have a lump removed. The reaction my wife gets when she tells friends is ‘Oh I’ve never heard of it in a man’, so she says «He’s got to be different»” (France et al., 2000, p. 345)</p> <p><b>Health Care System Level</b> “I was in to see the doctor and a surgeon a couple of years earlier when I had a lump. Basically, the surgeon said, “get out of my office, sometimes it’s better to leave your knife in your pocket”, after I hadn’t been in his office more than 30 s. He basically kicked me out. Two years later I could feel the flesh around the bump was getting kind of firm and I knew something was going on. I suspected that this was what it might have been all along. So, 2 years later he says, “Jeez, may be we should do something about it.” (Pituskin et al., 2007, p.47).</p> <p><b>Personal Level</b> I was ashamed at first [ ...]. Because men and breast cancer? [...] It’s the basis of several thoughts as: That could provoke mockery or strange questions. How can a man get breast cancer. [...] And I thought didn’t tell anyone at first (Midding et al., 2018, p. 2202).</p>
Fluctuating Emotional and Physical Reactions	“I suppose the fact that it was breast cancer surprised me. The fact that it was cancer I suppose was a shock.... So I suppose a combination of both. You know the fact that it was breast cancer which I don’t think I had heard of and the fact that it was cancer” (Iredale et al., 2006, p. 336).
Strategic and arduous disclosure	“I wouldn’t tell them on the phone. I had to, I had to, in myself I had to go and tell them, but I couldn’t actually get it out to tell them. It was a friend who had to tell them. When they, when they were told, because I had walked away, they both came and hugged me, which made matters worse for me then, I just ... I’d gone (started crying), you know” (Sime, 2012, p. 104).
Reconstruction of social beliefs and masculinities	“Men do not socialize diseases very well. One of our defective genes is the macho gene, and we very often fail to acknowledge that we can be a candidate for a disease, let alone a ‘woman’s disease’” (Halls, 2013, p. 128).
Uncertainty about and anticipating gender-specific treatment modalities	“The brochures I was given recommend things like ‘if you feel uncomfortable after your mastectomy, try a sleep bra, this may help. If you are feeling a little depressed while in hospital, put on a little make up or your favourite perfume’. This I could not comprehend and switched myself off” (Naymark, 2006, p. 162).
Feeling and experiencing being left out	“I’ve been the only men among women. An exchange of experience was not possible at the rehabilitation center” (Midding et al., 2018, p. 2200).
Using Self and Spousal Support and Resisting Social Support Systems	“Yes, yeah. And if it’s all women, they want to be talking theirs and, you know (pause) the male is gonna feel different in some way, so I’ll try and support men, but I couldn’t find any other men” (Sime, 2012, p. 157).
Discerning and developing contextual coping strategies	“You have to accept what it is like ... I always thought positive, always forward, you do not have to warm your head ... I feel calm like this, I was never nervous about it, until today everything is normal [ ...]. No good thinking bad things, I just thought of good things” (Duarte do Amaral et al., 2017, p. 1785).
Learning to live with altered body image	“I’m not ashamed of it, I’m not afraid of it, and I’m lucky. Well, I remarried after that, and I feel I’m still attractive – things like this happen to you, it’s not your fault. Not like people who disfigure themselves with rings and tattoos ...” (Pituskin et al., 2007, p.40).
Dealing with physical and sexual limitations	“I mean there’s no sexual relationship between my wife and myself and that’s very painful for her but she’s understands ... we have body contact er obviously and there are different ways of demonstrating love and affection rather than sex” (Quincey, 2017, p. 285).

awareness about BC in men (Pituskin et al., 2007). Iredale et al. (2006) reported that 80% (129/161) of men disclosed the diagnosis to their spouses but only 37% (60) disclosed it to their extended families. Those who disclosed the diagnosis to their family usually received emotional support and encouragement to disclose the diagnosis to others. Those

men used a strategic approach, which is, letting the spouse disclose the diagnosis to other family members and friends (Sime, 2012). The disclosure to extended families and friends was on a “need to know basis” (Quincey et al., 2016, p. 19).

The men’s disclosure was mostly received in a supportive way from



**Fig. 2.** The illness trajectory and transitional experience of men with breast cancer.

spouses, but in friends and extended families it was associated with feelings of “bewilderment and uncertainty” (Naymark, 2006, p. 162). The female friends were curious to learn more about MBC because they did not know that males can develop BC, while some men called out names to the men with BC, were shocked, showed disbelief, and sometimes refused to talk about it (Sime, 2012).

#### 4.3. Reconstruction of social beliefs and masculinities

Receiving the diagnosis of BC required men to re-examine their masculinity and others' social beliefs about masculinity. Halls (2013) calls this an attack on “hegemonic masculinity” and Quincey (2017) calls it “being under the radar”. BC being labelled as women's disease caused society to challenge men's manliness, their gender, and sexual orientation (Quincey et al., 2016). The diagnosis threatened their identity in society, where men seem to possess a macho gene; they have chests, not breasts; they cannot develop women's disease (Halls, 2013); and they are strong and invulnerable, hence they should not express any limitations and emotions (Duarte do Amaral et al., 2017). These men had this socially constructed view about themselves. With the diagnosis of BC, they were intrinsically forced to radically transform this image and accept that they are vulnerable to the women's disease. Some men lost their jobs, family roles, and social groups, hence they viewed BC as a personal failure (Quincey, 2017).

The men strived to contest the engrained social image of a real man and masculinity. A successful contest to achieve an identity transformation was dependent upon their social and financial status in the society (Sime, 2012; Quincey, 2017). Those men who had financially stable jobs, higher status, prior knowledge about BC in men, and inner urge to prove to others about BC, had greater chances of reshaping their personal and social views of themselves. This ongoing struggle to reformulate their masculine identities was also evident from the use of strategic disclosure, seeking help from spouses to help them in disclosure, and validating their diagnosis of BC to other men (Sime, 2012; Halls, 2013).

### 5. Transition stage 2: breast cancer management

#### 5.1. Uncertainty about and anticipating gender-specific treatment modalities

The men experienced a great degree of uncertainty in terms of BC management. Uncertainty is defined as the inability to determine meaning of illness-related events and inability to accurately predict any health care outcomes (Mishel, 1990). The men visited the clinics and health care providers with very limited knowledge about the possible treatments and were explicitly informed that they would receive treatment similar to that of women (Sime, 2012). Although the men were satisfied with the quality of services and care provided by health care providers (Donovan and Flynn, 2007; Sime, 2012), their health care providers did not know much about their treatment (Donovan and Flynn, 2007; Pituskin et al., 2007; Naymark, 2006). These men were uncertain about how they would be treated in the cancer clinics and desired more information about the available treatments. However, the need for information remained largely unmet (Donovan and Flynn, 2007; Iredale et al., 2006, 2007). Iredale et al. (2006) found that 56% (90/161) of men required more information about BC, the medical and nursing management, and other treatment modalities.

The primary source of information was health care providers who provided verbal information. Others used flyers, pamphlets, and internet to learn more about their conditions. However, they reported that the information provided by both providers and other sources was irrelevant to men (Donovan and Flynn, 2007; Iredale et al., 2006). Iredale et al. (2007) reported that 56% of men wanted more gender specific information that meets the needs of men with BC. Younger men were more likely to seek this information. The information on the flyers

and other documents was mainly about menstruation, wearing bras, and breast reconstructions, hence not of any help to men (Iredale et al., 2006). Overall, these studies noted that men wanted more gender specific and separate information and very often requested to see a photograph of other men with BC. Only Williams et al. (2003) reported that men wanted additional information on the flyers, rather than separate flyers for men with BC.

#### 5.2. Feeling and experiencing being left out

Throughout their treatment, men felt left out. Midding et al. (2018) reported that the men felt like “having the feeling of being the only rooster in the yard” (p. 2199). Female patients scrutinized these men in the waiting areas (Sime, 2012), gave them strange glances (Midding et al., 2018), and thought that these men were accompanying their spouses for emotional support (Sime, 2012). The men also had embarrassing interactions with health care providers. For example, the providers called them “Mrs” (Midding et al., 2018; Sime, 2012), providers provided preferential treatment to female patients and neglected their needs (Naymark, 2006; Quincey et al., 2016; Quincey, 2017), doctors labelled them with embarrassing titles “special men with BC”, refused a bed at the BC ward to prevent embarrassment to female patients, and denied emotional support (Quincey et al., 2016; Quincey, 2017).

#### 5.3. Using self and spousal support and resisting social support systems

The men used several mechanisms to deal with stigmatization and negative experiences during the disclosure and management stages. For emotional support, the men mainly relied on their spouses (France et al., 2000; Williams et al., 2003; Pituskin et al., 2007; Sime, 2012; Halls, 2013) and their personal abilities (Sime, 2012; Halls, 2013; Duarte do Amaral et al., 2017). The men re-examined their masculinity and sought to foster personal strengths to deal with the challenges of living with BC (Pituskin et al., 2007). After surgeries, the men rarely sought support and help from health care providers and friends and extended families (Williams et al., 2003). Iredale et al. (2007) reported that only 19% (31/161) of men sought support from other men. Some men did not seek help from providers because they thought they did not have adequate information about MBC and most of the campaigns are for the support of female patients. Some men reported seeking help from families (Sime, 2012), but others felt embarrassed and fearful because of the social stigmatization (Midding et al., 2018).

Regarding social support groups, some men expressed an interest and desire to join social support groups (Iredale et al., 2006). For example, Iredale et al. (2007) reported that 27% (43/161) indicated a desire to join support groups with men and women. However, most men did not want to attend any support groups (Pituskin et al., 2007; Sime, 2012; Quincey et al., 2016; Quincey, 2017). The most common reasons for refusing to participate in these groups was the “pink ribbon culture”, a campaign to provide awareness about and social support to women with BC. The men indicated that due to the strong association of pink colour with women and the pink culture campaign, men cannot get adequate representation and attention during their social support (Halls, 2013). Other reasons for not attending any social groups were: lack of opportunities to join the group, lack of trust in the usefulness of such groups, lack of men in support groups, and perceived inadequacy of the support groups to help them relate to others' experiences (Sime, 2012).

#### 5.4. Discerning and developing contextual coping strategies

The men experience various degree of psychological stress, anxiety, and depression before, during, and after BC. Brain et al. (2006) reported that 23% (35/161) of men reported high levels of cancer specific anxiety and low levels of anxiety (1%, 2) and depression (6%, 9). The

hospital related anxiety (Mean = 7.17, SD 4.36) and depression (mean = 5.09, SD 3.80) was noticeably high in men during BC management. Pituskin et al. (2007) reported that most of the men experienced unbearable emotional stress at the diagnosis and the management stage, but they managed it through positive thinking (Pituskin et al., 2007; Duarte do Amaral et al., 2017), denial, acceptance (Duarte do Amaral et al., 2017), and distraction (Brain et al., 2006; Iredale et al., 2007). The use of the coping strategies was contextual and based on the circumstances. The men would analyze the contextual factors and then plan accordingly to deal with the situation. For example, in the health care environment men usually downplayed the effect of cancer, stating that it is worse in women (Sime, 2012) and in social support groups with women they shared their emotions (Halls, 2013). To cope with the embarrassment of body scars, men either ignored people's strange expressions (Pituskin et al., 2007) or quit swimming (France et al., 2000).

## 6. Transition stage 3: survivorship

### 6.1. Learning to live with altered body image

After undergoing surgical and medical management, altered body image was the prime concern (Duarte do Amaral et al., 2017; Sime, 2012; Quincey et al., 2016; Quincey, 2017). The mastectomy scars affected men's sense of manhood leading to emotional stress (Pituskin et al., 2007) and disturbance in some routine activities such as swimming and sunbathing (France et al., 2000; Donovan and Flynn, 2007), while others indicated that it did not affect them because they accepted it as a part of their life (Sime, 2012). The men indicated that learning to live with the scars is the best they can do. Some compared the mastectomy scars with those of women, downplaying their scars as not as prominent as they would be in women. Others were offered cosmetic surgeries, but they refused (Sime, 2012), and some others rationalized that living with these scars is better than having tattoos and rings (Pituskin et al., 2007; Sime, 2012).

### 6.2. Dealing with physical and sexual limitations

The use of medicine and hormonal therapies resulted in changes in men's lives especially in terms of quality of life (Ruddy et al., 2013), mental and emotional health, and physical and sexual limitations (Andrykowski, 2012). Men reported loss of libido (Sime, 2012), hormonal symptoms, and sexual dysfunction (Andrykowski, 2012). For example, Ruddy et al. (2013) reported sexual satisfaction scores of 43.5 (SD 20.1) following endocrine therapy. Due to decreased libido, men were concerned about their sexual and married lives and some indicated the use of and discussion about the use of Viagra (Sime, 2012). Others indicated that their sexual lives have changed and they focus more on building relationships and appreciating their spouses in different affectionate ways (Quincey, 2017).

Regarding physical limitations and quality of life, there seems to be decrease in the quality of life and increase in physical limitations. For example, Andrykowski (2012) reported that, compared to men without BC, men with cancer had poor life satisfaction (1.78, SD 0.76 vs 1.53, SD 0.55, Effect size 0.41), poor physical health (3.15, SD 1.19 vs 2.70, SD 1.07, Effect size 0.40) and limitations in physical, emotional, and mental activities (47% vs 22%, OR = 3.17; CI = 1.76–5.71). Conversely, other qualitative studies indicated that most of the men specified that despite decrease in life quality and limitations, they have learned to appreciate other aspects of their life. For example, Pituskin et al. (2007) found that some men experienced a closeness to their families and friends and Quincey (2017) reported that men engaged in awareness campaigns and social activism for raising awareness of BC in men.

### 6.3. The core theme: persistently dealing with physio-psycho-social stigmatization

Men experience physical, psychological, and social stigmatization at three levels: social and community level, health care system level, and personal level. The social and community stigmatization influences the health care system level stigmatization, and both of these resulted in personal stigmatization. The social and community stigmatization largely results from inadequate public knowledge about BC in men (Midding et al., 2018; Naymark, 2006). It entails the public perception that BC is a women's disease leading to sexual stigmatization in society, blatant ignorance about the presence of this disease in men, calling out these men as queer, showing disbeliefs about BC, questioning men's mental state, and outrightly rejecting and implicitly calling them liars (Sime, 2012; France et al., 2000; Quincey, 2017).

Such stigmatized opinions about men led to stigmatization in the health care system, when they visited their general practitioners, nurses, cancer care centers, and clinics. Men described that health care professionals interacted with them "stoically" (Williams et al., 2003), the general practitioners considered them hypochondriacs and ignored their symptoms (Pituskin et al., 2007). Most of the men reported stigmatization in the cancer health care system. Midding et al. (2018) found that the greatest stigmatization was experienced in the cancer care settings (Mean 1.5, SD 0.96) particularly during hospitalization (Mean 1.2, SD 0.6). While visiting the clinics for their regular examinations and treatments, men indicated that they were requested to use a separate room for sitting, and separate entrances and exists to avoid creating an uncomfortable environment for female patients (Donovan and Flynn, 2007).

This societal and health care stigmatization resulted in self-stigmatization in these men. Their negative social and health care experiences negatively influenced their views of themselves. The men experienced both overt and covert self-stigmatization. The overt stigmatization was evident as some men considered themselves "biologically flawed" or "contaminated" (Donovan and Flynn, 2007), and the "odd ones" (Midding et al., 2018). They rejected seeking social and emotional support (Quincey, 2017). The covert stigmatization was apparent when they delayed seeking health care because of the ill-knowledge that men cannot develop BC. Despite that some men were aware of MBC (Sime, 2012; Halls, 2013), but they delayed their visit to the practitioners until they experienced extreme symptoms such as pain. They also feared facing stigmatization and marginalization due to disclosure of their diagnosis (Midding et al., 2018).

## 7. Discussion

This review unraveled the multifaceted experiences of men with BC at the diagnosis, during management, and during survivorship. Most of the studies originated from the UK, US, and North America indicating a dearth of research in Asia, Europe and Africa. With incidences of BC in men (Giordano, 2018), further research is needed from these regions of the world. The generated themes illuminated the complexities and challenges of men with BC and the negative effects on their personal and social lives. Prior to this review, we anticipated that men with BC may feel overwhelmed due to the nature of their diagnosis and the disbeliefs concerning MBC. However, we did not expect that the men with feel stigmatized and rejected in the health care settings merely based on their diagnosis. Due to lack of public and health care providers' knowledge of BC in men, men with BC experience a delay in diagnosis, which lead to worse physical, psychological, and emotional consequences. The review found that men were stigmatized at various levels and despite some positive experiences, men generally experienced an array of negative experiences which could be considered a direct consequence of social, health care, and self-stigmatization. Studies (Quincey et al., 2016; Midding et al., 2018) provided an account of stigmatization of men with BC in general, using indirect measures of

feelings of exclusion (Midding et al., 2018). However, further research is warranted to explore the stigmatization at two levels particularly at the level of the health care system and self. Midding et al. (2018) described stigmatization at the health care level of German men with BC, but research is needed in other eastern and western settings. The discovery that men experience more stigmatization in the cancer care system, that health care providers lack gender specific information on BC, and that providers fail to meet the care needs of men is a concern. The men reported being marginalized in clinical settings, being excluded from clinics, and that women receiving a preferential treatment in the unit wards. These negative experiences of men with BC are consistent with men with other types of cancer who experience marginalization in health settings at the hands of care providers (Handberg et al., 2015; Handberg et al. (2016)). Handberg et al. (2016) men with cancer felt left out and received limited health information compared to women in cancer rehabilitation settings. Therefore, nurses ought to be more cognizant of the needs of men with BC. It is important that despite a low prevalence of MBC, health care providers should be made knowledgeable about MBC and measures should be taken to ensure that men are provided holistic care. The nurses in the outpatient clinics assure that male patients are not marginalized and their concerns are adequately listened to and managed. The nurses in the inpatient oncology and surgical settings should assure that male patients feel respected from the hospital staff. The nurses can do so by advocating for male patients, carefully considering their needs, and practicing compassion and kindness when interacting with them. The hospitals can support the nurses' work by developing pamphlets and brochures outlining information about MBC and their challenges in health care settings.

The stigmatization at the social level resulting in hidden fears also prevents men from disclosing their illness beyond their immediate family members. This results in men using more negative (avoidance and denial) than positive coping strategies. Therefore, there is a need for social and cultural awareness of these challenges to men, and for the actions at social and health care levels to promote the well-being of men. The gender related stigmatization undoubtedly influenced men's experiences of BC and required them to manifest their masculinity in different ways. The men continuously challenged the stereotypical social image of men and raised their voices against the gendered view of BC. The gendered view was further evident from the pink ribbon culture and its negative influence on men reached to social and community support groups. The pink ribbon culture refers to raising awareness about BC and denoting pink color to BC, which symbolizes women. There is a need to raise awareness about MBC using blue ribbon, the color denoted with men (Quincey et al., 2016; Quincey, 2017). Therefore, it is imperative to comparatively study experiences of men and women with BC and the various experiences at different stages of transition. Sime (2012) compared the experiences, but the findings for women were drawn from a secondary dataset and may have limited transferability. These differences were not fully discussed in this review because of its distinct focus. Therefore, further reviews could focus on comparing the experiences of men and women.

After recovery, the men very often reported a disturbed body image and sexual and physical limitations. The sexual limitations could be more problematic for younger men than for the older men. Given that BC is diagnosed at a later stage in life, the sexual limitations may not be a matter of great concern in these men's life. This is also evident from the finding that men tend to focus more so on using other potential ways to demonstrate affection. However, altered body image can result in further emotional and social stressors, thus requiring further exploration. Of 17 studies, only 3 studies exclusively focused on understanding the survivorship experiences of men, their stressors and coping mechanisms, and the impact of BC on their family and social lives. Two of these studies were quantitative (Andrykowski, 2012; Ruddy et al., 2013) and did not provide detailed findings and one qualitative (Duarte do Amaral et al., 2017) was rated as weak. This indicates a dearth of

research on survivorship experiences particularly the long term social and family experiences. Therefore, further research could explore this area.

### 7.1. Limitations

The review focused on men's experiences from diagnosis to survivorship and did not present a comparison of the experiences of men and women. The studies which focused on the experiences of gay and bisexual men were not included so the findings are not generalizable to these populations. The literature is mainly from the western countries, therefore it is not transferable to eastern countries and developing countries, where there may be under reporting of MBC. Although measures were taken to ensure minimal researchers' bias during data analysis and synthesis, subjective interpretations were made which could have introduced unintentional bias at any stage of the review. The inter-rater agreement was assured to minimize this limitation.

## 8. Conclusion

Gender inequalities and stigmatizations regarding BC exist at personal, health care, and social and community levels. These stigmatizations negatively influence men's experiences of living with BC, from the time to diagnosis until survivorship. The men continuously strive to reconstrue their masculinity and use personal strengths and family support to manage their illness. The greatest stigmatization is experienced during the management stage; hence men mostly receive limited holistic care. Therefore, to confront and resolve gender inequalities in BC management, the nurses and other health care providers should focus equally on the needs of men and women with BC. The unique and essential needs of men entail reduction of health care and social stigmatizations, more gender specific information regarding BC care and management, and opportunities to participate in support groups. There is a need to ensure the provision of all gender inclusive cancer services to patients with BC. Regarding research, most of the studies were conducted in the western countries, hence it is important to develop a comprehensive understanding of men's experiences in various cultures and contexts. The research pertaining to the experiences and challenges of men with BC during palliative care is lacking, hence further research is warranted in this area also.

### Conflicts of interest

None Declared.

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